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THE INFLUENCE OF CARE TIME ON THE LEVEL OF KNOWLEDGE OF CAREGIVERS FOR PEOPLE SUFFERING FROM MULTIPLE SCLEROSIS.

Wpływ czasu sprawowania opieki na poziom wiedzy opiekunów osób chorych na stwardnienie rozsiane na temat istoty choroby.

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Abstract (in Polish):

Cel pracy

Zbadanie wpływu czasu sprawowania opieki na poziom wiedzy opiekunów osób chorych na stwardnienie rozsiane na temat istoty choroby.

Material i metody

W pracy zastosowano metodę sondażu diagnostycznego. Narzędzie badawcze stanowił autorski kwestionariusz ankiety. Badanie miało charakter anonimowy i udział w nim był dobrowolny. Grupę badaną stanowiło siedemdziesiąt sześć osób sprawujących opiekę nad swoim krewnym chorym na stwardnienie rozsiane. Warunkiem włączenia do badań było sprawowanie opieki przez opiekuna minimum 5 lat. Badania przeprowadzono na przełomie lat 2015 i 2016 na terenie Oddziału Neurologicznego z Pododdziałem Udarów Mózgowych w Wojewódzkim Szpitalu Podkarpackim im. Jana Pawła II w Krośnie. Analizę wyników przedstawiono za pomocą statystyki opisowej jako wartości liczbowe i procentowe. Zmienne jakościowe porównano za pomocą testu χ^2 , przyjmując poziom istotności $p < 0,05$.

Wyniki

Analiza statystyczna wykazała, że najwyższą wiedzę na temat najczęstszych objawów stwardnienia rozsianego posiadają opiekunowie ze stażem opieki w przedziale od 5 do 10 lat (36,4%). Najwyższy procent badanych (68,2%) z grupy sprawującej opiekę nad chorym od 5 do 10 lat deklarował MRI jako kluczowe badanie diagnostyczne w rozpoznaniu SM. Wiedzą na temat wieku, w którym najczęściej ujawnia się choroba wykazali się ankietowani z kategorii osób ze stażem opieki od 5 do 10 lat (59,1%).

Wnioski

Istotnie najwyższą wiedzę na temat najczęstszych objawów SM posiadają opiekunowie z najkrótszym stażem opieki. Czas sprawowanej opieki nie wpływa istotnie na wiedzę badanych w zakresie czasu pojawienia się pierwszych objawów SM.

Abstract

Aim

To study the influence on the level of knowledge of caregivers for people suffering from multiple sclerosis.

Material and methods

The study was conducted by applying the method of diagnostic survey-the author's questionnaire as a research tool. The participation in the study was completely voluntary and fully anonymous. The research group consisted of seventy-six people caring for their relatives who suffer from multiple sclerosis. Inclusion criteria in the research for potential participants were to be a caregiver for a minimum of 5 years. Studies were performed at the turn of 2015 and 2016 at the Subcarpathian Regional Hospital of John Paul II in Krosno at the Department of Neurology with subdivision of cerebral strokes. The results of analysis were presented using descriptive statistics as numbers and percentages. Qualitative variables were compared with the χ^2 test assuming the significance level of $p < 0,05$.

Results

The statistical analysis has shown that the highest level of knowledge about the most popular symptoms of multiple sclerosis can be identified with caregivers dedicated to multiple sclerosis sufferers for the period of 5-10 years (36.4%). The highest per cent of people under investigation in this group (68.2%) has declared that MRI is the key diagnostic examination in multiple sclerosis identification. 59.1% of respondents have also indicated the knowledge concerning age when the disease is most frequently recognized.

Conclusions

Caregivers with the shortest care time have the greatest knowledge about the most popular causes of multiple sclerosis. Care time doesn't have great influence on the level of knowledge about the first symptoms of the disease.

Keywords (in Polish): wiedza, stwardnienie rozsiane, opiekun.

Keywords (in English): knowledge, multiple sclerosis, caregiver.

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Short title

Czas opieki a poziom wiedzy opiekunów na temat SM.

Authors (short)

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Introduction

Multiple sclerosis (from Latin Sclerosis Multiplex, SM) is a disease affecting the central nervous system which is characterized by numerous infection focuses of gliosis scars in the white matter and demyelination. In the pathogenesis of the disease you can identify comorbid autoimmune, genetic and

environmental determinants [1-2]. Multiple sclerosis affects mostly young people who are in their peak shape, aged between 20 and 40, and is considered to be the most popular neurological cause of disability [3]. Multiple sclerosis is one of the most complex neurological diseases when it comes to the course, the diversity of symptoms and the methods of treatment. The disease may have different forms: benign, asymptomatic and progressive leading to disability. Bouts and remissions appear initially in the majority of patients. White people living in the mild climate regions are most prone to be affected by the disease [4]. Somatic symptoms of multiple sclerosis include disorders in the sphere of sensation, seeing, sphincter and cerebellum activities as well as cognitive functions [3]. Due to the chronic nature of the disease and problems in the functioning of a patient in all spheres of life, they require help and care. A caring role is one of the most basic family functions, particularly essential when a disease affects one of its members. This supports a patient in their daily fight with the disease consequences. Healthy members take on a role of caregivers which, without any knowledge concerning care rules and procedures, can be burdening and less effective [5]. Knowledge about the essence of the problem, its course and diagnostics shapes family participation in the process of treatment and rehabilitation.

Aim

The aim of the thesis has been to study the influence of care time on the level of knowledge of caregivers for people suffering from multiple sclerosis.

Material and methods

The research was based on the method of diagnostic survey. The author's survey questionnaire was used as a research tool. The study was anonymous and participation in it – volitional. 76 people taking care of their relatives suffering from multiple sclerosis took part in the study. The participation in the study was conditioned by care time for the period of minimum 5 years. The study was conducted at the turn of 2015 and 2016 in the neurological unit with the cerebral strokes section in the Regional Subcarpathian Hospital named after John Paul II in Krosno. The level of knowledge of the respondents was assessed on the basis of some questions included in the survey questionnaire and aggregated in the index form. For every answer the respondents were awarded 1 point (a correct answer) or 0 points (an incorrect answer). After calculating the points, the general index value could range from 0 to 6, where 6 meant the complete knowledge concerning multiple sclerosis. The high level of knowledge was established at the index value of 5 and 6. The low level of knowledge was set up at the index value of 0 and 1 whereas all the other respondents were classified into the category of the medium level of knowledge. The results analysis was presented in the form of numbers and per cents using the descriptive statistics. Qualitative variables were compared with the χ^2 test, assuming the significance level of $p < 0.05$.

Results

The majority of respondents (53.0%) were women whereas men accounted for 47.0%. The most numerous age group consisted of the respondents aged 40-49 (34.0%) which was followed by the respondents aged 50-59 (32.0%) and then those aged 60+ (26.0%). The least numerous group of respondents were caregivers aged 18-39 (8.0%). The majority of participants (57.0%) came from the country whereas 47.0% lived in small towns. In terms of vocational activity, working people constituted the majority (53.0%) and were followed by pensioners (43.0%) whereas students and the unemployed accounted for just 4.0%. In the study the length of care time over patients was considered to be the most important independent variable.

Relatively even division of the respondents was established in three categories of care time: 5-10 years, 11-15 years and above 15 years. In the author's study it was shown that the vast majority of caregivers (81.6%) declared the lack of knowledge concerning the most popular symptoms of multiple sclerosis. Much lower response rate of caregivers reporting the lack of knowledge concerning the most popular symptoms of multiple sclerosis was recorded with caregivers for the period from 5 to 10 years (63.6%).

Tab. 1. The respondents' knowledge concerning the most popular symptoms of multiple sclerosis

The knowledge of the most popular symptoms of multiple sclerosis:	care time period – 5-10 years		care time period - 11-15 years		care time period – above 15 years		in total	
	N	%	N	%	N	%	N	%
yes	8	36,4%	3	10,3%	3	12,0%	14	18,4%
no	14	63,6%	26	89,7%	22	88,0%	62	81,6%
in total	22	100,0%	29	100,0%	25	100,0%	76	100,0%
statistical significance:	$\chi^2=6,65763$, $df=2$, $p=0,035836$							

N = number of respondents

The knowledge concerning the MS key diagnostic examination is statistically conditioned by patients' care time. The study showed that less than half of the respondents (40.8%) declared MI examination whereas 31.6% mentioned CT and 27.6% - electroencephalography. The biggest number of responses showing MRI as the basic diagnostic examination in multiple sclerosis was reported in the group providing care for the period of 5-10 years (68.2%).

Tab. 2. The respondents' knowledge concerning the key diagnostic examination in recognition of multiple sclerosis

Which medical examination is key in recognition of multiple sclerosis?	care time period – 5-10 years		care time period - 11-15 years		care time period – above 15 years		in total	
	N	%	N	%	N	%	N	%
EEG	3	13,6%	10	34,5%	8	32,0%	21	27,6%
MRI	15	68,2%	7	24,1%	9	36,0%	31	40,8%
TK	4	18,2%	12	41,4%	8	32,0%	24	31,6%
in total	22	100,0%	29	100,0%	25	100,0%	76	100,0%
statistical significance:	$\chi^2=11,1920$, $df=4$, $p=0,024489$							

N = number of respondents

The knowledge concerning the essence of the disease was analysed. The majority of respondents (55.3%) described multiple sclerosis as a chronic, inflammatory and demyelinating disease whereas the rest of them (44.7%) gave incorrect answers. Some essential differences in the area of respondents' knowledge were identified, especially those classifying multiple sclerosis as a chronic, inflammatory and de-

myelinating disease affecting the central nervous system. Indeed the group of caregivers providing care through the period of 5-10 years (72.2%) gave correct answers more often than the others, i.e. those taking care of patients for the period over 10 years. Moreover, those respondents who provided care for the period 11-15 years gave incorrect answers more frequently than others ($p=0.013904$).

Tab. 3. The respondents' knowledge concerning the classification of multiple sclerosis as a chronic immune and demyelinating disease of the central nervous system

Categories	care time period – 5-10 years		care time period - 11-15 years		care time period – above 15 years		in total	
	N	%	N	%	N	%	N	%
a chronic inflammatory and demyelinating disease of the central nervous system	16	72,7%	10	34,5%	16	64,0%	42	55,3%
incorrect answers	6	27,3%	19	65,5%	9	36,0%	34	44,7%
in total	22	100,0%	29	100,0%	25	100,0%	76	100,0%
statistical significance:	$\chi^2=8,55120$, $df=2$, $p=0,013904$							

N = number of respondents

Among the incorrect answers the respondents identified mental diseases (36.8%) and civilization diseases (7.9%).

Tab. 4. The level of respondents' knowledge concerning the essence of multiple sclerosis

In your opinion, multiple sclerosis is:	care time period – 5-10 years		care time period - 11-15 years		care time period – above 15 years		in total	
	N	%	N	%	N	%	N	%
a chronic inflammatory and demyelinating disease	16	72,7%	10	34,5%	16	64,0%	42	55,3%
a psychiatric disease	4	18,2%	16	55,2%	8	32,0%	28	36,8%
a civilization disease	2	9,1%	3	10,3%	1	4,0%	6	7,9%
in total	22	100,0%	29	100,0%	25	100,0%	76	100,0%
statistical significance:	$\chi^2=9,44946$, $df=4$, $p=0,050796$							

N = number of respondents

Some further analysis didn't prove any statistically significant influence of the length of care time on the level of respondents' level of knowledge in the area of the disease forms. The vast majority of respondents (89.5%) do not know the forms the disease may take. The greatest knowledge in this aspect was identified in the group of 5-10 year-time caregivers. The differences appearing in this area of knowledge were not statistically significant ($p=0.226590$).

Tab. 5. The level of respondents' knowledge concerning different forms of multiple sclerosis

Do you know the forms of multiple sclerosis?	care time period – 5-10 years		care time period - 11-15 years		care time period – above 15 years		in total	
	N	%	N	%	N	%	N	%
yes	4	18,2%	1	3,4%	3	12,0%	8	10,5%
no	18	81,8%	28	96,6%	22	88,0%	68	89,5%
in total	22	100,0%	29	100,0%	25	100,0%	76	100,0%
statistical significance:	$\chi^2=2,96923$, df=2, p=0,226590							

N = number of respondents

The study showed that the majority of respondents (52.6%) do not have any knowledge regarding the time when the first symptoms can be observed. However, the respondents providing care over their relatives for the period of 5-10 years had knowledge in this area (59.1%). The differences appearing in this element were not statistically significant (p=0.283909).

Tab. 6. The level of respondents' knowledge concerning the age of patients when multiple sclerosis appears

The age of patients when the disease appears:	care time period – 5-10 years		care time period - 11-15 years		care time period – above 15 years		in total	
	N	%	N	%	N	%	N	%
20-40 years old	13	59,1%	14	48,3%	9	36,0%	36	47,4%
41-55 years old	9	40,9%	15	51,7%	16	64,0%	40	52,6%
in total	22	100,0%	29	100,0%	25	100,0%	76	100,0%
statistical significance:	$\chi^2=2,51820$, df=2, p=0,283909							

N = number of respondents

Also, the analysis dedicated to the influence of gender on the disease frequency ratio was carried out. The majority of respondents (57.6%) identified men as more prone to multiple sclerosis. The greatest knowledge in this aspect was recognized in the group of caregivers with more than 15 years of care time (54.2%). The differences in this area were not statistically significant (p=0.106606).

Tab. 7. The level of respondents' knowledge concerning the influence of gender on multiple sclerosis

Multiple sclerosis more frequently affects:	care time period – 5-10 years		care time period - 11-15 years		care time period – above 15 years		in total	
	N	%	N	%	N	%	N	%
women	11	47,8%	8	27,6%	13	54,2%	32	42,1%
men	12	52,2%	21	72,4%	11	45,8%	44	57,9%
in total	23	100,0%	29	100,0%	24	100,0%	76	100,0%
statistical significance:	$\chi^2=4,47723$, $df=2$, $p=0,106606$							

N = number of respondents

The author's study presented that only 7.9% of respondents had the high level of knowledge concerning the essence of the problem. The majority of caregivers (52.6%) had the medium level of knowledge. A slightly greater number of people having the high level of knowledge (18.2%) was reported in the group of caregivers with the shortest care time. The low level of knowledge was identified in the group of 11-15-year-care time respondents.

Tab. 8. The level of respondents' knowledge based on the length of care time

The level of knowledge:	care time period – 5-10 years		care time period - 11-15 years		care time period – above 15 years		in total	
	N	%	N	%	N	%	N	%
low	5	22,7%	17	58,6%	8	32,0%	30	39,5%
medium	13	59,1%	12	41,4%	15	60,0%	40	52,6%
high	4	18,2%	0	0,0%	2	8,0%	6	7,9%
in total	22	100,0%	29	100,0%	25	100,0%	76	100,0%
statistical significance:	$r_s=-0,092528$, $p=0,426626$							

N = number of respondents

Discussion

Multiple sclerosis, as any other chronic disease, affects not only a patient. A caregiver plays an important role in the process in which a patient fights with the disease. The literature review shows that the biggest number of articles is devoted to the functioning of multiple sclerosis patients whereas there are no sources regarding research into caregivers' level of knowledge about the essence of the problem [6-10]. The results of the author's research concerning the influence of care time on the caregivers' level of knowledge show that the majority of respondents (52.6%) have the medium level of knowledge about the disease. Only among the respondents having 5-10 years of care time a slight percentage of people (18.2%) presented the high level of knowledge. Thus, it can be assumed that these caregivers found out about their

relatives' disease relatively recently and they learnt about the essence of the problem. And in the course of time, some information concerning the disease vanishes from caregivers' memory and they no longer feel the need of expanding and updating their knowledge.

The similar suggestion was made by [11] who presents that only 20.0% of caregivers for people suffering from multiple sclerosis declared some enthusiasm for expanding their knowledge regarding the course, diagnostics and treatment of MS as well as expressed their desire to learn about the nature of the problem from specialized literature. The author's own research shows that despite providing care over a patient for the period of 5 years, 57.9% of respondents declared that the disease affects men more frequently. Taking into consideration the level of knowledge about the forms the disease may take, it turned out that 89.5% of respondents don't know the form the disease may take. It should be noted that caregivers with 5-10 years of care time belong to the group displaying the knowledge about MS forms (18.2%). Also, caregivers for relatives over the period of 5-10 years could correctly identify the age at which multiple sclerosis appears. The similar concepts were formulated by [6] in her research. She presented that families of patients suffering from an inflammatory and demyelinating disease do not have enough knowledge in this respect.

Ochojska comes up with similar suggestions [12]. She proves that caregivers looking after patients do not have any elementary knowledge concerning the essence, the course, the diagnostics and the treatment of multiple sclerosis, no matter how long care time is. She also emphasizes the fact that caregivers are not enthusiastic about taking any action to acquire and expand this type of knowledge. It is noteworthy that all the duties which a caregiver may face when a family member gets ill are exhausting and difficult, requiring sacrifice and patience. Very often a caregiver may experience worry, fear, uncertainty or helplessness. They concentrate all their energy, physical strength and focus on a patient [13]. Despite the fact that behavior, symptoms and situations typical for the disease are very often not clear or understandable for caregivers, it is of little importance for them to expand or update their knowledge concerning the disease [14].

Conclusions

1. Care time over a patient suffering from multiple sclerosis does not influence the level of caregivers' knowledge concerning the essence of the disease.
2. The level of respondents' knowledge concerning clinical aspects of the disease can be described as medium.
3. The knowledge concerning the key diagnostic MS examination is conditioned by the length of care time over a patient. Caregivers with the shortest care time of 5-10 years are the most knowledgeable in this area.
4. The highest level of knowledge concerning the most popular MS symptoms can be attributed to caregivers with the shortest care time.
5. No statistically significant influence of the length of care time on the respondents' knowledge concerning the form of the disease has been shown.
6. The length of care time does not significantly influence the respondents' knowledge in the area of age at which the first MS symptoms appear.

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